**Additional file 1: Table S1.** Survey questionnaire for TSC caregivers/families

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| **Questions** | **Choices presented** |
| 1) Have you/the patient ever had a mental health/neurocognitive assessment, or filled out a TSC-Associated Neuropsychiatric Disorders checklist? | * No
* Once (ever)
* Once every 3 years
 | * Once a year
* Twice a year
* Every 3 months
 |
| 2) Do you feel that your/the patient’s psychiatric/neurocognitive requirements were appropriately managed by the physician? | * No
* Somewhat
 | * Mostly
* Yes
 |
| 3) Who/what raised the issue of TSC-Associated Neuropsychiatric Disorders (mental health or neurocognitive issues) with you/the patient? | * You/family member
* Teacher
* Rehabilitation professional
* Physician
 | * TSC specialist
* A screening process
* Other (please specify)
 |
| 4) How easy is it for you/the patient to obtain a psychiatric assessment, if required? | * Easy
* Difficult
 | * Very difficult
* Not required
 |
| 5) How long have you/the patient been on a waiting list before being seen by a TSC specialist? | * 0 – 3 months
* 3 – 6 months
* 6 – 9 months
 | * 9 – 12 months
* > 12 months
 |
| 6) How easy is it for you/the patient to obtain continuing psychiatric therapy, if required? | * Easy
* Difficult
 | * Very difficult
* Not required
 |
| 7) How effective do you consider the collaboration between your/the patient’s mental healthcare team, and the rest of your healthcare team to be? | * Ineffective
* Somewhat effective
* Mostly effective
* Very effective
 |
| 8) How does it feel for you/the patient to be referred for psychiatric assessment/treatment, compared with other healthcare assessment/treatment? | * The same
* More negative
* More positive
 |
| 9) Answer (a) or (b) as applicable:1. If you/the patient has not previously received psychiatric treatment for TSC: Do you think that psychiatric treatment could improve the quality of life for TSC patients and their families?
2. If you have/the patient has previously received psychiatric treatment for TSC: Do you think that psychiatric treatment can improve the quality of life for TSC patients and their families?
 | * Yes
* No
* Unsure
 |

TSC, tuberous sclerosis complex